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Functional, Motivational And Emotional Support: A Qualitative Study Of Social Influences On Diabetes Management Among Low-Income Adults

Emily Helen Miron
emily.miron@yale.edu

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Emily H. Miron

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Advisor/Committee Chair: Danya Keene, PhD

Committee Member: Soohyun Nam, PhD, APRN, ANP-BC

Abstract

Objective To understand how low-income adults living with type 2 diabetes conceptualize and utilize social support in their diabetes management.

Methods The data for this paper came from a larger qualitative study, conducted by the advisor and last author, exploring the intersection of housing access and diabetes management among 40 low-income adults diagnosed with type 2 diabetes in New Haven, Connecticut. This qualitative study utilized 58 of the previously collected semi-structured interviews (some participants were interviewed more than once). Excerpts from two broad parent codes from the original study were analyzed using a flexible and iterative coding process.

Results Participants conceptualized diabetes management as a "battle" that is taxing mentally, emotionally and physically. Understanding the magnitude of diabetes management, participants often relied on their social networks for assistance. Social influences greatly aided but, in some instances, hindered diabetes management through three main domains of influence: functional, motivational and emotional.

Conclusion and Implications Diabetes self-management is a lifelong process with life or death implications. The nature of diabetes management can be taxing and burdensome for individuals as it requires both behavioral and medical interventions. Participants detailed how their social support networks mitigated many stressors associated with their chronic disease management via functional, motivational and emotional support. Future research should explore how social support networks can be more routinely incorporated into diabetes management and effectively utilized to promote health and well-being especially for low-income populations.

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Introduction

Type 2 diabetes, the most common form of diabetes, accounting for 90-95% of cases, is a chronic condition in which the body does not produce or properly use insulin. Insulin is needed to convert sugar, starches and other foods into energy. In the United States, approximately 9.4% of the U.S. population is living with diabetes and 33% is living with prediabetes ("National Diabetes Statistics Report", 2017). It is no secret that diabetes is a major public health problem. Diabetes is the seventh leading cause of death in the United States, accounting for more than 80,000 deaths annually ("Leading Causes of Death", 2017). Low-income populations are up to two times more likely than high-income populations to have diabetes ("National Public Health Survey", 1998; Robbins et al., 2001; Stelmach et al., 2005). In addition to the disproportionate burden of diabetes among low-income populations, individuals of lower socioeconomic (SES) have worse glycemic control, more diabetes related complications and higher mortality (Saydah et al., 2013; Stevens et al., 2014).

The American Diabetes Association defines diabetes self-management (hereafter called diabetes management), as an "evidenced-based ongoing process of facilitating the knowledge, skill and ability for diabetes self-care" based on an individual's "needs, goals and life experiences" to promote problem solving, informed decision making and self-care (Funnell et al., 2008). Successful diabetes management requires both lifestyle (e.g. diet and physical activity) and medical (e.g. insulin or oral medications) interventions to control blood sugar levels. Yet, access to lifestyle and medical management resources is not universal for all people. The sociocultural (social support and cohesion) and environmental (physical, economic, and policy) conditions in which individuals live either enhance or constrain individual health choices and behavior (e.g. ability to participate in physical activity, eat nutritious foods, drink water

regularly, consume and afford high-quality healthcare and medication) (Al-Goblan et al., 2014; Dendup et al., 2018). For example, low-income populations are up to two times more likely than high-income populations to have diabetes as they generally do not have access to the same resources, including time and money, to consistently incorporate recommended lifestyle interventions in their diabetes management ("National Public Health Survey", 1998; Robbins et al., 2001; Stelmach et al., 2005).

The nature of diabetes management can be taxing and burdensome for individuals as it is a lifelong process with life or death implications. Social support is known as an important factor in mitigating some of these challenges and has shown to positively influence health and well-being (Reblin & Uchino, 2008). Social support, defined as "support accessible to an individual through social ties to other individuals, groups and the larger community" and includes emotional, financial, functional and informational support (Gallant, 2003; Tang et al., 2008). The link between social support and health is generally explained through two main models: the "direct effect" and "indirect" or "buffering" hypothesis (Stopford et al., 2013). Meaning that social support systems affect health outcomes directly through the networks themselves or indirectly by shielding an individual from negative events. Research has shown that social support may be particularly beneficial in promoting resilience and buffering against some of the challenges associated with living in low income communities (St. Pierre, 1975; Portes, 1998). Low income communities are often composed of tight-knit and trusted networks of family, friends and neighbors which reciprocally provide each other with emotional (showing affection), informational (knowledge of systems/resources and advice) and instrumental (small monetary loans, transportation, child care, food) support (Brisson & Usher, 2007; Ahluwalia et al., 1998).

Some research has examined social support and diabetes management. These studies define social support in various ways including: amount of support received, satisfaction with the support, source of support or size of the support network (Tang et al., 2008). Schiøtz et al. (2012) found that among Danish adults with type 2 diabetes more frequent contact with friends was associated with increased levels of exercise. Other work by Tang et al. (2008) found that among 89 African American adults diagnosed with type 2 diabetes, positive social support, measured via the Diabetes Family Behavior Checklist-II, was associated with an increased likelihood of following a healthy eating plan and exercising at least thirty minutes in the past week. Additionally, participants that indicated feeling satisfied with their support networks were more likely to monitor their glucose levels over the previous week (Tang et al., 2008).

Despite previous findings on roles of social support in diabetes management, less is known about social support and diabetes management among low-income populations (Black et al., 2017; McContha et al., 2020). Low-income populations with type 2 diabetes may particularly benefit from social support because of a lack of access to quality preventative health care, greater psychological distress and limited financial resources to afford healthy foods (Kaplan, 2006). To address these gaps, the objective of this paper is to explore how low-income individuals with type 2 diabetes in New Haven, Connecticut conceptualize and utilize social influences in their diabetes management.

Methods

The data for this paper came from a larger longitudinal qualitative study, conducted by the last author, exploring the intersection of housing access and diabetes management among low-income adults in New Haven, Connecticut (Keene et al., 2018). The study was approved by the Yale University Institutional Review Board. Eligible participants included those that were

over age 24, currently diagnosed with type 2 diabetes and met subsidized housing eligibility income criteria. Flyers at community locations such as public libraries, social service offices, bus stops and the housing authority aided in recruitment. Forty adults participated in semi-structured interviews from July 2016 to January 2017. Interview questions focused on the unique challenges, resources, and strategies used to co-manage diabetes, low socioeconomic status and potential housing instability. Among interview participants, the average age was 51 years, 19 participants (47.5%) identified as female, 6 were currently homeless (15%) and all were taking oral medications or insulin to manage their diabetes. Each interview lasted between 45 minutes and 2 hours. Data was transcribed verbatim by a third-party vendor. Participants were compensated with $50.00 for their time.

The analysis for this paper was an iterative process using excerpts from 58 of the 60 previously collected interviews (some participants were interviewed more than once). Two interviews conducted and transcribed in Spanish were omitted from the sample for analysis because of the primary author's limited Spanish fluency. The initial excerpts for analysis included the broad parent codes: "Diabetes and Community", "Community Programs" and "Diabetes and Relationships" from the original study. In the original codebook "Diabetes and Relationships" was defined as "descriptions of social networks and sources of support for participant's diabetes management, as well as lack of social resources." Similarly, "Diabetes Community" was defined as "description of interactions among diabetics that facilitate support" and "Community Programs" was defined as "descriptions of social and community programs that have positive impacts on participants' experiences related to housing." These codes were not explored in-depth in earlier analyses of the data and provided insight into the role of social influences on diabetes management. Using Dedoose, the primary author open-coded all excerpts

from the aforementioned parent codes to review and identify concepts and themes related to social influences and diabetes management. After the open coding process and discussions with the research team, the primary author decided to omit the "Community Programs" excerpts and focus on the "Diabetes and Community" and "Diabetes and Relationships" excerpts because they proved to be most directly related to the research question.

The primary author used the "Diabetes and Community" and "Diabetes and Relationships" excerpts to develop codes and themes related to social influences on diabetes management. The primary author used these codes and themes to develop a draft codebook. At this time the primary author decided to define social influences for this analysis as the "informal" or "unprofessional" networks participants regularly associated with such as partners, children, extended family, friends, fellow persons with diabetes etc. rather than those involved in more "professional" or "clinical" networks of care such as doctors, nurses, social workers, nutritionists or care managers to better understand how social support systems impact coping with and adherence to diabetes management. Of note, the analysis is focused on how these persons impact diabetes management rather than their relationship to each participant. After reviewing this codebook with the primary advisor and research colleagues during weekly qualitative research group meetings the codebook shifted from broadly looking at positive and negative social influences to three more analytical themes and categories of influence: functional, motivational and emotional. The primary author continued to modify the codebook after re-reading and modifying child codes to include more analytical themes and categories. The final codebook was then applied to all excerpts and reviewed by the primary advisor and last author to ensure appropriate identification and application.

Results

The following sections describe social influences on diabetes management among low-income participants. Diabetes management is complicated, taxing and time consuming. Understanding the magnitude of diabetes management, participants often relied on their social networks for assistance. Social influences greatly aided but, in some instances, hindered diabetes management through three main domains of influence: functional, motivational, and emotional. To protect the anonymity of participants, potentially identifying information, including names, where provided, have been changed and when discussing the results below.

Functional

Participants described the ways in which their support systems made the medical and behavioral aspects of their diabetes management easier. For example, Regina detailed how helpful it was when her partner organized and prepared her medication and reminded her of proper doses. She said, "He fills my medicine box up, all my medicine, he makes sure that everything is set where it's supposed to be, my insulin and stuff, my needles, everything. That's my rock. He's been great, his family has been great, too."

Other participants whose family members, friends, or roommates were also persons with diabetes discussed creating routines together to manage their insulin and improve medication adherence. For example, Nate noted how it was "easier" to manage his diabetes while living with a partner who was also had diabetes. In comparison to his previous living arrangements, he said,

> "Easy. Get up every morning, pricking fingers and taking medication. It was pretty easy because we know this is what we have to do when we get up in the morning. You've got to check your blood sugar. You have to take your medication. And throughout the day you have to check your blood sugar and take your medication. And watch what you eat. It's routine."

Many other participants discussed how their social networks reminded them of health supporting choices regarding proper nutrition and medication adherence. For example, Janet said in reference to her mother, “She is an alarm clock. Janet, take your medicine. Jan, you don’t eat that. Okay ma. Ugh. She’s a big support.”

Similarly, Melissa’s young son often accompanied her to her diabetes support classes in which they learned about diabetes-friendly recipes and how to properly read nutrition labels. He also sometimes commented on less healthy items picked out at the grocery store saying,

> “Well ma, you think you need that,” you know? And it’s good for somebody to say, you know, to reinforce you because sometimes I would like to cheat and sometimes, I do but you know with somebody saying, “Oop, ma, what’s that in the carriage for? Put that back.”

Melissa was “pleased” that her family supported her by choosing healthier food options.

The importance of social support was underscored by the challenges participants faced to keep up healthy habits, such as exercise, when their support systems who participated in these routines were unavailable or moved away. For example, Shirley said,

> "R: I used to do a lot of walking. I don't really have anybody to walk with me now, so. Well, we used to just get up every morning before work and walk. Four miles. And then go to work. And I did that for years, until my partner moved away. Then anybody else that I know didn't really have that, wanna just get up and just do that. She was a friend, but she wasn't really from my neighborhood. But we would meet each other and then go walking.
>
> I: Yeah. And did you do that before you were diagnosed with diabetes, or –?
>
> R: No. Mm-mmm.

I: Did you do it because you knew it would help with the diabetes?

R: Yes. Mm-hmm.

I: That sounds great. When did she move away? When did you stop walking?

R: Some years ago. I walked off and on a little bit. But it wasn't like every single day. Like, we did every day. We never missed."

Physical activity and other lifestyle changes have been shown to be effective at controlling type 2 diabetes and curbing prediabetes. Walking is a simple, effective and affordable way to build physical activity into one's daily life. Having an exercise partner generally improves accountability, morale and retention to exercise routines. Shirley's story underscores the importance of having an exercise partner and the potential negative health effects of not having one.

Although the majority of participants found their social support networks to aid in their diabetes management, some social influences made it more challenging. Lacking autonomy in certain social interactions hindered participants' ability to engage in healthy behaviors such as eating nutritious foods. Participants discussed the challenges of trying to maintain healthy habits when living with or visiting others who did not make their diabetes as much of a priority. For example, Regina detailed,

"It was Thanksgiving every day in that woman's house, let me tell you, yes. She cooked like that. So when you're living with somebody, you really can't say, 'you know I got diabetes and I can't eat that,' 'cause one time I joked around with her, I said, 'you eat _____,' she said, 'if you don't push back from that table, you just gonna keep on eating, you gonna blow up.' I said, 'well, I don't have another choice, because look what you cooking, you make me eat like that.' So she goes, 'I don't make you eat like that, you eat it

> on your own.' But when you in somebody else's house, you have to respect what they cook and stuff 'cause what they'll say is, 'you don't have to eat it,' but I gotta eat something. But it's a whole lot different 'cause now, when you in your own place, you can cook that healthy food now, you can have that healthy stuff."

As Regina describes here, food is a culture that brings people together. There are often rituals and underlying "rules" associated with eating with others such as "respecting" (eating) what others prepare for you. For persons with diabetes, this lack of autonomy in social interactions, often involving food, is stressful and potentially dangerous if they cannot or feel like they cannot eat healthier alternatives.

Motivational

Participants also described how social networks could increase or affect their motivation to stay on top of their diabetes management. Some explained that they felt motivated to take care of their diabetes so they would be able to spend quality time with loved ones. For example, Diane discussed how she thinks of her care management in the "big picture" and its impact on her partner and children. She said,

> "I don't want to die – yet. I know I'm going to die, but I can do what I could do in order for me to stay alive. So I stay on top of my medication and like I say, I stay on top of Martin (her partner). I want us to grow old and walk on a walker together and eat soup and crackers and things like that, telling the cats to get off our lawn, you know? I think of that. I think of the long run, the big picture. So I stay on top of it. I see how my kids were when my mother died. I don't want them to have to go through that so soon with their mother."

Participants often discussed how there was a turning point in their diabetes management when they realized that they did not have to face diabetes alone and that their lives, health and wellbeing were intimately tied to others. This realization helped them understand how their networks influence their care and inspired them to prioritize their diabetes management.

Another way that social networks affected prioritization of diabetes was by seeing negative health outcomes from those in their social networks who did or could not. Mike, responding to a question about what led him to be more careful about his diabetes management said,

> "Well, anyway, I just wanted to maintain myself. I didn't want to face those other things. I've been – I've seen a lot of different people lose limbs, lose toes – as a matter of fact, my friend, Mike did. He had diabetes and he wasn't taking care of himself. Well, anyway, I went to see him in the hospital, but he was doing drugs and stuff and eating whatever he want, and everything else. They amputated one toe, then they took one of his legs below his knee, and then a few years later, he just passed away from it, because he just wasn't taking care of himself or anything else. So, when I seen all that, and I know that this is going to happen to me, so I need – to prevent all that, this is what you need to do."

Mike's sentiment echoed similar ideas from several participants. By witnessing grave losses associated with uncontrolled diabetes such as eyesight, toes, and even life, the reality of the seriousness of diabetes set in for participants. Mike and other participants internalized this fear, and its implications, and thus were motivated to take care of themselves and manage their diabetes to the best of their ability.

Emotional

Participants frequently commented on the emotional support their networks provided as participants described diabetes management as a “battle” that few win alone. Participants even suggested that there should be emotional support groups for persons with diabetes that touch on important aspects of diabetes management beyond physical needs like nutrition and medication. For example, Regina said,

> “Yeah 'cause the ones that I know (diabetes support groups), it's more physical support like your health, they show you how to do this but I would like -- I love the idea of that but I would also love the idea of having something emotionally, where you could talk how we are, like you could have a support group for diabetics, emotionally, where they could sit and talk and stuff. Like I said, being a diabetic, it takes a toll and not just physically. It takes a toll on a person mentally. So that would be good if they had a support group like that.”

Emotional support most often manifested itself by support systems inquiring about a participants’ emotional state and needs. Diane recalled,

> “But my niece, she's four. And she said, "Auntie, do you need medication?" If my head hurt of something, "You need medication, auntie?" And if you say you don't feel good or whatever she comes in and rubs your head or rubs your back or whatever.”

Diane’s niece’s gestures-the verbal inquiry and physical touch- are manifestations of love by attuning to and checking in on another’s thoughts, feelings and states. By doing this, she helped relieve some of the “mental toll” of diabetes, as Regina described above, for her Aunt, Diane.

Other participants described the usefulness of more intense or stern forms of reminders from their networks. For example, in response to the question of what makes it easier to stay on top of your diabetes Diane said,

> "Remembering what it feels like when I'm hurting. Like before I do something Milton will show me the picture of me in the bed when I was in the hospital. He say, "Remember this?" I was crying, scared. So he said, "Remember that? You going to end up back there." Some days that stop me from doing silly things."

Although Milton's comment may seem harsh, Diane appreciated his frankness which spurred her to care for her diabetes. Participants recounted that when their support systems reminded participants of diabetes related difficulties they experienced in the past, it reinvigorated the reality of complications and need for stricter adherence to their management plan.

While for most participants social support was helpful and useful in their diabetes management, for some participants, too much social support or an overstepping of social support was viewed as an annoyance and unhelpful. For example, when an interviewer asked Bella if there was anyone she found helpful to manage her diabetes, she said, "No, they (her friends) truly annoy me. I get pissed when they're on my case and I know it's for my own good but I don't wanna hear that every time I'm going to put something in my mouth." Bella's sentiment echoes the notion that when social influences become overbearing and annoying participants may backlash against their health promoting recommendations and disengage in self-care behaviors like eating healthy and regular exercise.

Discussion

The narratives provided in our interviews highlight the multitude benefits, with few downsides, of social influences on diabetes management. Participants described the ways in

which their support systems provided functional, motivation and emotional support. Functional support that aided in medication adherence included medication organization and establishing blood sugar reading routines. Social networks also reminded participants about healthy food choices. Notably, some social influences negatively impacted diabetes management. Lacking autonomy associated with social gatherings, especially involving food, made participants feel like they did not have the ability to control what they ate. Participants also described how lacking social support, especially exercise partners, limited their ability to exercise regularly. Social networks also provided great motivation for diabetes management through two pathways: living for others and internalized fear. Finally, participants viewed the emotional support they received on a spectrum from checking in to tough love and nagging. Whereas checking in and tough love aided in diabetes management nagging did not. The overbearing nature of nagging backfired for participants as they disengaged in the health supportive recommendations their networks suggested.

Understanding the nuances of social influences on diabetes management is vital to unpacking how social support plays an important role in chronic disease management and how these networks can be effectively utilized in the future to promote and sustain health and well-being especially for economically vulnerable (low-income) populations.

Limitations

These interviews and the subsequent analysis of social influences on diabetes management demonstrated how low-income adults in New Haven, Connecticut, conceptualize the role of their social networks in their diabetes management and how these networks both mitigate and contribute to the challenges associated with it. Qualitative research, including semi-structured interviews, inherently give power and agency to participants by allowing them to

share their own story. And yet, this study is not without its limitations. Firstly, as mentioned before, the data from this study came from a larger study exploring housing access and diabetes management. Thus, social influences and diabetes management were a subtopic that came up during the first open coding process and not specifically nor systematically probed for in the interview guide. It is plausible that participants did not discuss social influences on their diabetes management as often or as in as much depth as they may have if it was included in the interview guide, and that some mentions of social influences may have been overlooked in the coding process and thus not included in this analysis which relied on excerpts of previously coded interviews. Secondly, eligibility criteria for this study included low-income persons who were eligible for subsidized housing-a particularly vulnerable population. Studying social influences on diabetes management among this population is both a strength and a potential weakness of the study. Housing instability compounds challenges associated with navigating diabetes among persons of low socioeconomic status. Therefore, it is plausible that the support networks of participants and their mechanisms of influence are unique and not representative of other low-income populations. Future research should focus on unpacking social influences on type 2 diabetes management among all low-income persons. Despite these limitations, this study adds to the literature and understanding of social support and its influences on diabetes management.

Future Directions: Implications for Research and Practice

These interviews point to the potential benefits of emotional support groups for persons with diabetes in local federally qualified health centers (FQHCs), community clinics or other organizations. Participants described their disease management as a "battle" that takes a "physical and mental toll", but knowing persons in their network cared about them and their health took some of their stress away and "makes you want to do better."

Although these interviews suggest that the majority of social support from any source was beneficial to participants, there was some support and lessons only fellow persons with diabetes could provide. Support networks made up of fellow persons with diabetes aided in medication adherence by establishing routines with others to check blood sugar levels and administer medication, and motivated participants to adhere to their medication, exercise and nutrition guidelines as they served as examples of the potential of negative health outcomes if they did not. It is likely that fellow persons with diabetes could provide emotional and psychosocial support to each other in unique and needed ways as they are all fighting similar "battles". Future research should explore the range health benefits of emotional support groups for people with diabetes. This understanding would be useful in further assessing the feasibility of creating such groups and the impact they would have on participants, the organization(s) hosting the groups and health care system.

Although not directly mentioned by participants, these interviews and analysis suggest that it may be useful for providers to routinely ask about a patient's social support networks upon diagnosis of type 2 diabetes and also followed up on thereafter. Inquiring about and leveraging social support is a standard practice in other areas of medicine. For example, before a surgery, a clinical team usually asks about the support systems a patient has to assist in their recovery process because studies have shown that patients experience a smoother recovery process and improved health outcomes if they are supported by others (King et al., 1993; Kulik & Maher, 1989). For example, studies exploring social support amongst persons receiving hip and knee replacements found that intra family dynamics and familial support are important determinants for joint recovery (Theiss et al., 2011). Recovery from surgery requires a short burst of social support. Which begs the question, what does adequate and effective social support look like for

chronic diseases like diabetes (Kadirvelu et al., 2012)? This study and others like it have demonstrated the influence of social support on diabetes management (White et al., 2012). Understanding what a patient's support networks are like at the onset of their diabetes could lead to a better understanding and management of their disease, which would not only improve their health outcomes but also potentially reduce costs associated with serious diabetes complications like stroke, amputations, neuropathy and kidney disease for the healthcare system.

Conclusion

Diabetes management is a lifelong process with life or death implications. The nature of diabetes management can be taxing and burdensome for individuals as it requires both behavioral and medical interventions. In this study, low-income persons with diabetes detailed how their social support networks mitigated many stressors associated with their chronic disease management via functional, motivational and emotional support. Future research should explore how social support networks can be more routinely incorporated into diabetes management and effectively utilized to promote health and well-being especially for low-income populations with diabetes.

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